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Cover Page:

Understanding kidney transplant patients' treatment choices: the interaction of emotion with medical and social influences on risk preferences.

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Abstract

Following renal transplantation patients experience on-going immunosuppressant medication to reduce the risk of graft rejection. Over the long term the side effects of immunosuppressive drugs may affect graft survival and significantly increase risks of cancers, stroke and cardiovascular disease. To reduce these risks research is underway to develop a biomarker test to identify those patients who are likely to be 'tolerant' to their graft and therefore able to reduce immunosuppression. Biomarker tests may however incorrectly identify some patients as tolerant, thus jeopardising their graft. Following a quantitative assessment of risk preferences we undertook a qualitative study to investigate the range of influences that shaped the substantial variations found in the level of risk transplant recipients were hypothetically willing to take. In-depth interviews were carried out in the United Kingdom between May 2013 and July 2014 with 24 transplant recipients all of whom had stable kidney graft function. These interviews identified a range of factors that patients take into account when making risk assessments, including familial views, trust and the ritual of 'gift exchange' that permeates the social space of kidney transplantation. Our data support the notion that emotion is not part of a linear process, preceding and separate to reason, but is intertwined with personal understanding and perception of risk and involves a complex interplay between different influences on decision-making. Our data also support Lupton's view that risk judgements are shared and collective rather than located within the individual and suggests that patient choice rather than involving a purely rational weighing of medical benefit is often based on influences that may not accord with the framework nor intention of medical professionals and medical

research.

Keywords: United Kingdom; kidney transplantation; biomarker; risk; emotion; social influences; 'gift exchange'; trust.

1. Introduction

Since the early 1960s sociologists have considered the health hazards associated with the introduction of innovative forms of medical treatments and therapies as constituting a veritable 'risk epidemic' (Schlich & Trohler 2006:2). This 'manufactured' form of risk, produced by innovative developments in science and technology, has little historical reference arising instead with the process of modernization and influencing the manner in which we conceptualise and manage risk (Giddens 1999). Ulrich Beck argues that in the late modern period, with the 'fracturing of monolithic sources of knowledge and identity in contemporary Western culture', reliance on the 'calculability' of risk has been increasingly challenged (1992:71). This is due to the rise of modernity having produced situations of risk for which experts do not have answers. As a consequence many opinions are expressed and the ability to 'calculate' risk, once based on the 'true' knowledge of the expert, dissolves leaving people to 'estimate' the risk. As such the way we come to a decision now involves individual beliefs, behaviours and 'everyday life' and whatever evidence we find most believable (Tulloch & Lupton 2003; Wasserman & Hinote 2011). This means that decision-making is a complex process when faced with biomedical initiatives that bring both the hope of unimaginable advances yet the possibility of

often significant negative consequences such as the clinical trial of the immunomodulatory drug TGN1412 during which catastrophic systemic organ failure occurred (Goldacre 2013). Testing of these new technologies and treatments requires service users to engage with the risk of the unstable and complex framework of scientific claims.

1.1 Framing the concept of risk

Disciplines frame and understand the concept of risk differently. For example the life sciences and medicine apply principles, postulates and calculations to address what is perceived as the *objective* reality of 'risk' whereas psychology views risk as a behavioural and cognitive phenomenon and focuses on judging risky *behaviour* (Zinn 2015). In contrast anthropologists see risk as a cultural phenomenon, including the way in which risk is publicised and moralised (Althaus 2005) and sociologists emphasise risk-taking as a form of social action based on experience and tacit knowledge (Zinn 2008 & 2015). These disciplines also have varying notions of the influence of emotions on decision-making in situations of risk. The psychologist Paul Slovic argues that emotion is important in *guiding* judgement and decision-making, with people drawing on a pool of conscious or unconscious associations that are marked to varying degrees with positive or negative feelings (Slovic 2007). Emotion is thus seen from this perspective as preceding and separate from what is described as reason (Slovic & Vastfjall 2010). Although these perspectives on risk may be relevant to elements of our findings it is Deborah Lupton's argument that 'emotion and risk *interact* in the process configuring each other' that we argue most keenly reflects our findings (Lupton 2013:641). Lupton regards risk judgements as

imbued with emotion, whether this is at the pre-conscious, unconscious or conscious level and depicts emotion and risk as inevitably configured via social and cultural processes (Lupton 2013:634). Thus although risk may be material, as in a risk to health, it is always interpreted via a social or cultural lens. Lupton describes this in terms of an 'emotion-risk assemblage' that both incorporates notions of affect into the concept and also identifies the ways in which the social and its cultural manifestations shape risk perceptions and decision-making (ibid:636). However, Lupton notes that the relationship between risk and emotion remains under theorised, particularly in the context of health and medicine (ibid:637). Taking up Lupton's conjecture we therefore consider both the place of emotion and social influences on the choices made by kidney transplant patients when faced with a biomarker test.

1.2 Our study

Our empirical study focuses on the process of decision-making in kidney transplant patients in the context of on-going research to develop a biomarker test to identify those patients who can be considered 'operationally tolerant' to their graft and who will therefore not experience rejection in the absence of immunosuppressive drugs (Heidt & Wood 2012); the term biomarker being defined as 'a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention' (OECD 2011). It is anticipated that identifying the 'biomarker of tolerance' will improve the present situation where immunosuppressive drugs taken to reduce the risk of kidney graft rejection may

in themselves damage the graft and also cause long-term health problems including cancers, stroke and cardiovascular disease (NHS 2015a; Howard et al 2002). However, biomarker tests are not 100% accurate with the risk that patients may be *erroneously* identified as tolerant. In these circumstances withdrawal of immunosuppressant medication could lead to the rejection of the graft. In this situation a patient centred approach to the research requires both to weigh the medical benefits of minimizing immunosuppression against the risk of precipitating graft rejection *and* to identify how patients conceptualise, interpret and respond to the risk in the context of their experiences and the priorities of their life world.

The paper forms part of a larger project with the initial stage employing a quantitative approach to identify the level of risk that kidney transplant patients might be willing to take in choosing biomarker led care. In percentage terms this identified hypothetical risk levels ranging from 0% to 50%. The second qualitative phase, reported here aimed to elicit the variety and interaction of influences on their risk decisions.

2. Method

Participants for the qualitative study were purposively selected from the initial quantitative patient sample to include differences in age, gender, type of transplant and time on dialysis. Ethical approval was obtained for the research following which a research nurse at each of the eight participating hospitals initially contacted patients to establish whether they would be willing to consider taking part in the study. Patients who agreed were sent a letter describing the biomarker research,

making clear that the test was not 100% accurate and explaining that the purpose of the study was to identify the level of risk that patients may be willing to take. The first author (JH) then telephoned to discuss the study, answer any questions and for patients who agreed to be involved, set a suitable date and time.

Interviews took place in people's homes, cafes or occasionally a meeting room within a Hospital Trust. Informed consent was obtained from all participants following provision of an information sheet and opportunity to ask questions. It was also emphasised to participants that their participation was voluntary and they could withdraw at any stage. Interviews began with participants sharing the 'story' of their renal failure and kidney transplant(s) to elicit the context of their decision-making. The researcher (JH) then explored issues that participant's raised. Other considerations were also probed assisted by a topic guide designed to elicit patients' attitude to risk, including personal priorities - past, present and future - views on the biomarker test and the level of risk they would be prepared to take if the test showed they were 'tolerant' and could hypothetically have their immunosuppressant medication reduced. The interviews took place over 15 months and most lasted 45-60 minutes. Three interviews were carried out in the presence of a patient's relative – wife, husband or mother – whose voices are brought into our findings. Following 24 interviews it appeared that saturation point had been reached with no new themes emerging.

Analysis occurred concurrently with interviews. Initially the taped interviews were transcribed verbatim and pseudonym(s) assigned. Preliminary coding and thematic

analysis were then undertaken and the data entered into the software package NVivo9 to benefit from the automated search and display facilities. Each transcribed interview was then worked through manually to achieve a more complete understanding of the fluid and creative ways that themes emerge (Welsh 2002).

3. Findings

The participants comprised 24 kidney transplant patients aged between 28 and 68 years from diverse backgrounds (Table 1). No one characteristic appeared to separate those who would take a low risk – expressed as between 0% and 5% - or those willing to take a risk of 20% or more.

In what follows we maintain 'risk' terminology (Jackson, Allum & Gaskell 2006:2) by using the concepts of 'downsides' and 'rewards' to consider participants perceptions of biomarker led care. We then describe the themes of 'trust' and familial perception that formed significant considerations although neither a downside nor reward. The figure in parenthesis following a participant's name represents the level of risk they were hypothetically prepared to take if identified as tolerant.

3.1 Downsides of the risk

Fear of graft failure is known to have a major influence on the lives of kidney transplant patients (Howell et al 2012) and our participants similarly described how the maintenance and retention of their graft was an ever-present goal. It was therefore understandable that many spoke of not wishing to tamper with their medication, often using idioms to capture the sense of maintaining the "*status quo*".

For example Lorna (1%), after twelve years without rejection, did not view "*interfering with the situation*" as an option:

> *I just know I've not had any rejection ….. . And I just assume, you know, the kidney must be tolerating what I'm being given ….. . So what I say is let sleeping dogs lie!*

Likewise Miranda (0%) was not about to disrupt her medication considering her graft allowed her to carry on her chosen lifestyle:

> *Well having had this brilliant kidney for eighteen years, there is nothing I would do to risk its health. I really wouldn't ….. no, even at the hospital, if they said, 'We're going to change your anti-rejection tablets now,' I'd be very, very wary of changing them. I think it's got into a nice routine now, it's comfortable, I don't want to rock-the-boat. And I can't bear….., I couldn't bear the thought of life without it.*

Apart from in general not wishing to 'meddle' with their medication, patient's specific perceptions of the positive and negative aspects of the risk often reflected their personal circumstances and experiences. For example, Tom (25%) revealed a history of poor health commencing at age 3 with a diagnosis of leukaemia; understandably in these circumstances he focused on the medical advantages of tolerance. In contrast, Paul (0%) with two young sons and a mortgage focused on the fear of not being able to meet his "*responsibilities*" should rejection of his graft occur. For Jessica (2%) who suffered very few medication side effects and was pregnant the

194 risk of rejection was not something she would entertain, although appreciating the
195 long-term negative side effects of immunosuppressants. James recently married and
196 with his career just taking off, did not wish to disturb the feelings of "*control*" that
197 the transplant gave him, despite suffering bouts of diarrhoea that he knew to be
198 medically induced.
199
200 As part of the fear of graft failure many of our participants spoke of the dialysis that
201 would ensue. Twenty participants had experienced dialysis with ten expressly
202 identifying it as a factor in their decision. For some the thought of returning to
203 dialysis caused considerable emotional concern with patients speaking of the regime
204 as "*life limiting*"; "*a remover of freedom*"*; "an awful, awful experience"*.
205
206 For Jack (0%) having spent 25 years on dialysis the notion of taking a risk was
207 inconceivable: "*If you've done two or three years and had a transplant, I don't think*
208 *you appreciate the sort of possibility of doing really long-term dialysis."* As Jack
209 explained, he and his wife Mary would only take part if the test was 100% accurate.
210 Similarly for Alice (25%) the idea of "*being strapped*" to a dialysis machine felt like
211 "*the end of my life"*, a *"death sentence".* Alice told how in order to avoid dialysis she
212 and her medical team took the risk of performing a pre-emptive kidney and pancreas
213 transplant. Jessica (2%) who was on haemodialysis also recounted dialysis in very
214 emotional and negative terms speaking of the way the transplant had "*transformed*"
215 her back to her "*normal self*".
216

The most common form of dialysis is haemodialysis that uses an external machine to filter blood of waste products whereas peritoneal dialysis uses the inside lining of the abdomen as a filter (NHS 2015b). Both forms of dialysis are considered to have advantages and disadvantages (Wasserfallen et al 2004). Jenny (10%) for example chose to have peritoneal dialysis but retrospectively felt this to be intrusive:

> *Maybe it was the dialysis I chose, quite intrusive and also a little bit demoralising. I didn't feel whole because I constantly had a reminder ….. you know, it's not normal that you cannot go without a tube sticking out of your stomach. Or you can't go somewhere because you've got to go home and do your bag.*

James (0%) however pre-emptively chose peritoneal dialysis to avoid the permanent fistula related to haemodialysis:

> *And I chose ….. to go with the peritoneal dialysis, so that I had it at home mainly because I didn't want to have the fistula in the arm for life ….. with the peritoneal I could lead a normal life.*

Dialysis as a downside was therefore aligned with a poorer quality of life, limited freedoms affecting how participants lived their lives and challenging "*normality*". However, the risk of a return to dialysis - even following a poor previous experience – could be felt to be worthwhile if the reward was considered to be great enough. For example Mark (50%) described his prior experience of being "*hooked"* up to a machine for eight or nine hours a night as *"horrendous" …..* but it was a risk he was

willing to take in order to lead *" ….. a life without drugs ….. to be able to be normal".* *As he explained:*

> *you never feel well ever ….. . It affects your social life, your emotional and personal life, sexual life ….. . Just the thought of it* [dialysis] *is horrendous. ….. you can't go away without this, that and the other. The spontaneity disappears from your life essentially*.

Although dialysis was generally viewed as a negative experience, or one to be tolerated, some participants such as Georgina (35%), although not wishing to return to dialysis, told us her trips to the hospital for haemodialysis had brought "*enjoyment*" through the company of other patients and the excellent nursing care she received, including *"the tea and buttered toast".* Georgina's account of the positive elements of her previous experience of dialysis indicates that one should not divorce medical procedures from either their social setting or the individuals circumstances and experiences, nor the effect these have on individuals conceptualisation of downsides and rewards.

3.2 Rewards of the risk

Whilst the disturbance of graft equilibrium, possible rejection and return to dialysis were spoken of as conceivable downsides these were often balanced with the imagined personal rewards of engaging with the risk. Firstly there was the reduction in drug side effects. This was important for Mark (50%) and it was also important for Tom (25%) who had experienced repeat urine infections, methicillin-resistant

263 staphylococcus aureus (MRSA) and septicaemia and stated *"I would buy into that …..*
264 *to move away from that* [repeat infections], *would increase my quality of life".*
265
266 However most participants did not identify the possibility of fewer side effects,
267 better graft function or long-term health as having a major influence on the risks
268 they were willing to take. This raised questions concerning how much transplant
269 patients are told about immunosuppressant drugs. The standard protocol aims to
270 ensure that all renal transplant patients are fully informed of the effect of anti-
271 rejection medication prior to transplantation (NHS 2015a). However, on speaking
272 with participants it was clear that often no further conversations about side effects
273 took place. The first author discussed this with a leading consultant nephrologist
274 who raised the dilemma of stressing the negative side effects to patients when at
275 present there is no alternative to immunosuppressive drugs. His response was, "*We*
276 *don't want to upset the patients*". As medication non-adherence is a major reason
277 for graft rejection (Butler et al 2004) the situation highlights the trade-off with which
278 both patients and medical professionals have to contend.
279
280 A noted type of 'reward' for taking the risk of biomarker led care was meeting the
281 emotional desires to respond to the social norms of 'gift exchange'. Whereas the
282 personal benefits of reducing immunosuppressant side effects were less common
283 than we expected it was significant that 15 of the participants described the concept
284 of "*giving back*" as a reason to risk biomarker led care. Patients expressed how
285 "*lucky*" they felt that they had been given such "*an unbelievably precious gift"* or a

"*gift of life*" and moved from general sentiments, such as "*wanting to help*", "*doing my bit", and "paying back"* through to more elaborate explanations:

> William (50%). *Well it's just like a debt really. I just feel, I just …, I owe a debt, you know. It's like when somebody does you a favour. ….. I'd be happy to trial it* [biomarker led care]*, because like I said to you, I feel I owe something back to the people that have given me this freedom, this better life that I've had. …..*

Social theories of gift giving go back to the anthropologist Marcel Mauss (1954) whose work focuses on the way in which collective exchange practices create relationships and build social solidarity. However, examining the complexity of *contemporary* social gift practice Elder-Vass (2015) debates this 'exchangist' paradigm and argues that a vast amount of giving is not based on exchange but involves 'many different kinds of giving, with radically different social and political implications' (ibid:15). Classifying gifting into different forms he expounds on two. The first is 'positional giving' which is examined through the case of giving in families and similar intimate relationships. Elder-Vass describes this form of giving as fundamental to family life and it can be seen in the gifting of a kidney within close relationships. The second form is giving 'free gifts to strangers' (ibid:11). This we argue includes the anonymous donation of living and cadaveric kidneys and the willingness to be involved in clinical research from which one may not benefit. In relation to our study the giving of free gifts to strangers is of particular interest in two ways. Firstly having received an anonymously donated kidney many of our participants expressed a desire to reciprocate in some form. When this was in the nature of agreeing to participate in clinical research our participants often expressed

this as being for the "*benefit of future kidney transplant patients*" and not necessarily themselves. As Lorna (1%) explained:

> *The night I came in for my transplant, someone came to me and they said, 'Would you be interested in any research? …..* [I said] '*Yes, I would.' You know, and give back ….. And I was very pleased to – I felt as if I wanted to give something as what I was getting.*

The question of 'why' our participants wished to reciprocate when the gift of a kidney had essentially been made to a 'stranger' raises the notion of 'altruism'. Whether a person is 'straightforwardly' altruistic or feels that they, or possibly somebody close to them, may benefit from the altruistic act renders the concept complicated. In this case gaining benefit from the 'altruistic' act of taking a high risk with biomarker led care runs counter to the narrative of 'giving back' and brings in the notion of self-interest that has been argued tends to devalue the act of altruism (Nelkin 1998:36). However, there is also the notion that in our participants' case being willing to take a high risk is based on a form of '*interlocking obligations'* where a refusal to give - or in this case take a risk with biomarker led care - 'is to reject the bonds of alliance and commonality' (Douglas 1997:13). In this manner altruism may be seen as a calculated notion of potential benefits; an awareness of the inter-dependence of the system of research and medical advancement and the social responsibility of the role of 'kidney transplant patient'. Hyland (2009) points out that the fact that 'reciprocation' takes place *over time* – which requires the parties to cultivate a relationship - distinguishes the gift from the mere exchange which is reciprocated immediately and thus does not require, nor encourage, a continuing

bond between the giver and the recipient. Refusal to reciprocate a gift is equivalent to the denial of the relationship. In the case we are examining this seems very plausible in terms of the close relationship that patients have with the hospital and staff. From the kidney transplant patient's position the mandatory quality of the counter-gift is just as integral to the nature of the gift as its unilateral quality. Consequently a person who has received a kidney feels the urge to restore the balance to the extent that their self-esteem may rest on a successful reciprocation. Alan (50%) framed his desire in terms of "*benefitting others"* saying he would be prepared to "*go down to fifty-fifty ….. because if it killed me, the benefits would be there for others*":

> *….. there's my desire to learn ….. versus the desire to have as long a relationship with my partner as I can, and obviously family ….. And that's, the tension. ….. one, I want to help, yes I would dearly love to help … but on the other hand, if it means me losing years, you know, I'd have to think about that very carefully. So that's what that represents. You can't quantify it. I'm feeling it. That's what I'm feeling.*

Graham's explanation demonstrates a difficulty in articulating his emotional struggle between a strong social desire to "*help*" and an equally strong desire to maximise his life expectancy. For some however the tension between social integration and

personal risk was resolved by suggesting any adverse effect would be responded to rapidly, as Jenny (10%) explained:

> *I think because we were prepared to go through this, then we should get a bit of an easier ride back to the top* [of the transplant waiting list] *….. I'd be happier to give myself more freely with a backup plan. ….. I think if they can say, 'Right it's 90%, let's go for it, and we'll put you back at the top of the list,' then I'd be absolutely fine.*

The notion of 'giving back' within the data was therefore found to be complex with gestures potentially disproportionate to the physical risk of biomarker led care. Often participants revealed the internal negotiation of anticipated downsides and rewards. 'Giving-back' was hence emotionally charged, often linked to feelings of responsibility and '*doing the right thing*' and formed part of an assemblage of considerations that collectively configured the level of risk a patient was prepared to take.

3.3 The notion of 'trust'

Zinn (2008) describes trust as relying on experienced-based and tacit knowledge, which in turn is influenced by personal context and feelings or beliefs, producing a multi-layered concept. In the contemporary world, with its rising complexity, he views trust as increasingly required, including trust in experts with appropriate knowledge and skills (ibid:442). Certainly our data pointed to the prominence of concepts of 'trust', 'belief' and 'faith', reflecting Zinn's views that these notions are relied upon when clear evidence is unavailable. For example, a deeply emotional

relationship with a particular consultant led William (50%) to speak of "*complete faith*", "*100% faith"* in his hospital and medical team, "*trust(ing) them implicitly"*:

> *X* [name of consultant] *is like a godsend in my life. He's a god. He'd be there* [on the ward] *at half past seven at night on a Saturday and he'd just stroke your leg as if to say, 'You're going to be alright.' Excuse me* [Emotional]

Other participants used similar terminology. For example Alice (25%) described Zinn's notion of trust, combined with personal experience in terms of knowledge of medical advancement:

> *Because I have absolute faith in the fact that you are being supervised and because of the care ….. the medical care has been phenomenal. I just trust them and the way things are moving* [medical advancement] *they will just catch stuff, the medical teams and the surgical teams, I do just trust them. I have a very high level of trust.*

However our data indicated that faith and trust in a medical team did not necessarily translate into a willingness to take a higher level of risk. James at 0% stated:

> *I do value what they say ….. I've always really trusted them up here. They've looked after me really well. And I will often prefer to get their opinion on anything, not just my kidney problems, rather than seeing my GP or, you know, any other specialist.*

This however may reflect the importance of other factors in James' life including a desire to keep physically active and play sport and indeed he questions his own perspective:

> *I play golf, football, cycling. I've played eleven months with a kidney peritoneal dialysis tube. So I take risks in that way*. …. *But, yes, that's quite a weird one for me to think of, to be honest, because why don't I* [risk biomarker led care] *in that respect if I do play football with a peritoneal dialysis tube out of my stomach?*

Paul (0%) with a young family to provide for was also not prepared to take any risk with biomarker led care and echoed the conflict:

> *If they tell me it's black and white, it's black and white, to a certain extent. ….. I think they're brilliant, absolutely brilliant. As I said, they're like family.*

Paul's phrase "*to a certain extent"* indicates the tension and internal negotiation that runs through the process of decision-making where risk is concerned. With little scientific knowledge available to aid in the decision whether to risk biomarker led care our participants can be seen to evoke what Zinn (2008) terms the 'in-between' strategies of trust and emotion in balancing the level of risk they are prepared to take. Zinn argues that these strategies, including intuition, complement and overcome some of the limitations of calculative forms of risk management, facilitating effective control over the future and echoing Beck's (1992) argument that we now look to the 'estimability' of risk and that we use 'beliefs, behaviours and everyday life' in our decision-making (Tulloch & Lupton 2003).

6. Familial Perception

Mason (2004) argues that a misreading of personal narrative as an individualistic discursive form has fuelled the hold of the concept of individualism; a concept that permeates the medical world. This should be borne in mind when considering the manner in which families collectively consider the nature of innovative treatments and in our study was demonstrated by descriptions of patients negotiating risk-taking with their family. Robert (10%) having decided upon his level of risk told us "*I would take a much higher risk, but my wife would kill me!*" and Luke (0%) said "*I couldn't possibly say what risk I would take until I've discussed it with my wife and the family*". Many participants spoke about discussing any 'risky' treatments with family prior to making a decision. This supports the notion of 'family ethics' (Verkerk *et al* 2014) and highlights that responsibilities must be negotiated against the backdrop of family relationships, and treatment decisions made in the light of those negotiated responsibilities. It also raises the moral problem of whether the structure of contemporary medicine, including participation in clinical research, takes into account the demands it makes on families and how these demands have the potential to further embed patterns of social behaviour, conceivably injustices. By treating patients as individuals we ignore harms incurred by family members and may as a consequence damage relationships (Hardwig 1990).

We had envisaged that familial negotiation would be higher in the case of a living donation from a family member or friend. However, this was not evident in our data.

For example although Oliver (50%) and his mother had become "*closer*" since her donation this had not translated into a low level of risk taking:

> Pam: ….. *it would be obviously his decision. I mean he's saying that he would be more willing to take risks. I think I would be a little bit more reserved than that*.

It would appear therefore that it may not be the origin of the graft *per se* that leads to familial negotiation but for some the necessity to discuss risk within relationships. Luke whose wife donated a kidney to him 8 years ago explained:

> Luke (0%): *I know it's my body and all that, but it doesn't work like that. ….. we've been married now over thirty years, it just doesn't work like that. We're a team and I would never agree to something if she wasn't in agreement as well.*

Luke's comments echo our findings that regardless of whether participants received a donated kidney from a known source or a cadaveric transplant there is still a strong drive to discuss the situation with family. This was further illustrated by William (50%)

> *Put my name down first! How do you find out if it's accurate? You can't keep doing them on rats and mice, can you? You need somebody to be able to say, 'Do you know what, I'll give that a go.' Yes - my wife might not agree with that point of view …. I'm the one with the transplant and she's not, but she's*

the one who could be left with the children …… We'd talk about it and ultimately it would be mine and my wife's decision.

Jane, Alan's wife, who would be cautious of anything less than 100% test accuracy, shares the notion that decisions should be discussed with family:

I'm more selfish. ….. this is where the research hasn't been done, on the impact on families. ….. Alan comes from that point of view – 'Well I've had so much surgery, it would probably be quite quick, I'm never going to know, I'm not going to suffer.' But I've been at home with the kids on my own, done the emotional journey ….. been told, 'We don't know if he's going to pull through,' and it was really hard.

Despite the patient being treated by the medical profession as an individual, our findings indicate that decision-making where risk is concerned is often a negotiated affair, predominately with family members being more risk averse and causing the patient's judgement to be adjusted in favour of less risky behaviour.

4. Discussion

The introduction of innovative therapies that carry risks but also offer the potential of long-term medical benefit raises questions of what patients take into account when making treatment choices. Our interviews with kidney transplant patients provide empirical evidence in support of Lupton's notion of the 'emotion-risk assemblage' where decisions are configured through an accumulation of considerations that are interwoven by emotional affect. Regardless of whether a

494 participant chose to opt for a low or high level of risk it is apparent that the decision
495 was shaped through analysis of their social and medical situation *and* their feelings,
496 with risk being what Lupton described as the enactment of 'feelings' and 'analysis'
497 simultaneously (Lupton 2013:641).
498
499 With graft rejection being a major consideration for kidney transplant patients it was
500 understandable that many patients chose to continue with their current
501 immunosuppressant treatment. This was based on more than analytical decisions
502 with patients "feeling" that their graft was "*settled*", "*comfortable"* or "*in a nice*
503 *routine*", echoing the 'gut feeling' that Lupton speaks of (Lupton 2013:635).
504 Considering that one of the downsides to rejection may possibly be a return to
505 dialysis it is further reasonable to argue that the emotion of experience played a role
506 in patient's decisions.
507
508 For some people these emotional and practical considerations appeared to have a
509 strong influence on their risk preference, leading them to opt for the "*status quo*".
510 However a number of patients were prepared to take a higher risk drawn by even
511 stronger feelings or concerns. For a few it was a reduction in symptom burden and
512 the effect this had on their life. However the small number considering issues of
513 symptom burden and the adverse effects of immunosuppressive drugs may have
514 been influenced by a lack of in-depth knowledge of the drugs significant adverse
515 effects. In addition the study was restricted to patients with 'stable' kidney function
516 whereas patients with unstable function and a heavier symptom burden may have
517 perceived greater medical gain and been prepared to take a higher risk.

Whereas risk-taking has been linked to personality type (McDaniel & Zuckermann 2003) our data point to participants being prepared to take high risks in some areas of their lives, such as voluntary risk associated with sport, whilst taking a low risk with biomarker led care, reflecting that the social context of decisions about, and calculations of, risk are more persuasive. This concurs with Lupton's perspective on experiences that involve voluntary risk-taking, such as drug taking and participating in 'extreme sports', where risk-taking is not the product of ignorance or irrationality, but taken without coercion in the full acknowledgement that risks are being confronted for reasons of self-improvement, emotional engagement or control (Lupton & Tulloch 2010). Supporting this Stephen Lyng (2012) identifies how voluntary risk-taking produces heightened embodied sensations and emotions thus further demonstrating the complexities of the production and management of emotion in risk-taking.

Considering the prolonged relationship that kidney transplant patients have with their medical personnel it was understandable that 'trust' had a strong influence on attitudes and behaviours. According to Japp (2000) trust is necessary to generate a readiness for risk taking (Zinn 2006). In considering this we need to think carefully about the reification of the patient that occurs through the process of trust. For Taussig (1980) physical things, such as the therapies and the 'technology of healing' should not be considered as 'things-in-themselves' but also as signs and symbols of social relations that are disguised as natural things concealing their roots in human relationships. In Taussig's opinion by denying these human relations we reproduce a

political ideology in the guise of a science of (apparently) 'real things'. In essence Taussig is pointing to the social relations embedded in disease, and their therapies, and highlighting the synthesis of the moral, social and physical presentations. According to Taussig in modern clinical practice and medical culture this function is camouflaged, concealed by the aura of benevolence and to openly discuss that which is camouflaged would be to undermine the stability of the present clinical practice *and* to question the presently accepted relationship between clinician and patient. By doing so we would undermine a stable reality that cannot be denied as long as professional expertise bears down, as long as authorship is 'denied' and reciprocity makes its presence felt (Taussig 1990:5). Taussig's argument therefore brings into question the value of trust when intent is camouflaged. We did however note that trust does not necessarily lead to action, it could be voiced but did not necessarily translate into a high-risk level. This indicated that feelings of trust and faith may not preclude stronger emotions or rationales from shaping decisions.

The social space of kidney transplantation influences not only trust but also emotion and the desire to 'give back', to 'reciprocate'. In hospital renal clinics where conversations with medical professionals and indeed other patients focus on creatinine levels, drug adherence and other medically induced phenomena enrolments in clinical trials take place. One participant described the collective experience as requiring her to be the "*good kidney patient*". This we argue incorporates the notion of the patient as one who although aware of health risks - for example adhering to medication regimes) - is one who is prepared to take risks to be involved in medical research and one who *also* appreciates they are the recipient

566 of a 'gift' which as (Mauss 1954) describes carries its obligations to reciprocate.
567 These notions are important for as Lupton (2013) argues when patients weigh up
568 risks, or decide to take a risk, they are making assessments of the social meaning of
569 the phenomena, making sense of the situation and the risk. This takes into account
570 that although the risk may be material it is always interpreted via a social or cultural
571 lens reflecting amongst other things moral judgements within the particular
572 historical, social, cultural and political context (Lupton 2013b:638). Regardless of risk
573 levels many participants made reference to the obligation they felt to reciprocate in
574 some manner for the 'gift' they had been given. For some this went hand-in-hand
575 with a risk level of 50% raising questions concerning the central place of exchange
576 and co-operation in society and the role this plays in kidney patients agreeing to
577 participate in medical research. If one considers 'gift exchange' as a social fact then
578 Durkheim's argument (1982) is of great relevance, e.g. that the manner of acting,
579 thinking and feeling that constitutes the social fact (in our case 'gift exchange') is
580 invested with a coercive power by virtue of which it exercises control over the
581 individual. This line of argument may explain the almost sacrificial attitude of some
582 participants and alludes to the way that emotional appeal cannot be divorced from
583 decision-making, despite medicines focus on rational scientific thought. It also raises
584 questions concerning the loss of dignity if one is unable to meet the obligation of
585 reciprocity and how patients may feel this keenly during patient-doctor encounters
586 or amongst fellow transplant patients and donors.
587
588 Our participants were also aware that treatments for renal failure have improved
589 because of the willingness of patients to take a risk with new and novel approaches

590 and that they themselves might benefit from current research. Coupled with this is
591 the value reciprocation may have in obtaining resources needed for future life and
592 the maintaining of social bonds within the clinic. For example we need to understand
593 how patients perceive the relationship between research studies and organ
594 allocation and how this affects their risk judgement. This is of particular relevance to
595 kidney transplantation where organs fail and it is not unheard of for patients to
596 require up to three grafts.
597
598 Lupton describes risk judgements as shared and collective rather than located within
599 the individual (Lupton 2013:644). Similarly our findings reflect the affect that 'others'
600 perspectives have on the assemblage. These include health professionals together
601 with the influence of familial opinion, with risk levels often mediated to take into
602 account family feelings and responsibilities.
603
604 **5. Conclusion**
605 Our interviews with transplant patients support the notion that emotion is not part
606 of a linear process preceding and separate to reason but intertwined with the
607 understanding and perception of risk. Acknowledging the shaping of risk-taking in
608 this way helps to appreciate the interplay that occurs between different factors that
609 patients take into account when making risk assessments. It also challenges the
610 perception of risk-taking by patients as based purely upon a rational weighing of
611 medical benefit, for example the reduction of symptoms or improved long-term
612 health. By so doing the study raises important questions concerning the influence
613 that emotion, social structures and concepts have on the level of risk a patient may

be prepared to take when invited to enrol in clinical trials. It also opens up the possibility that patient choice is based on influences that may not accord with the framework and intention of medical professionals and medical research. Although Lupton reminds us that expert judgement is neither free of emotional involvement, and science itself is inevitably an emotional enterprise, there is still the need to consider the ways in which research within the arena of clinical medicine may produce a tension arising from a collision with patients and familial frameworks.

The field of kidney transplantation is to a certain extent peculiar in the medical domain with notions of repeated transplantation and requirements for organ donation. As a consequence the individual factors that influenced our participants' decision-making may not be applicable across medicine. However we argue that the notion of the 'emotion-risk assemblage' is and provides a tool to enable discussion and explanation of medical risk-taking particularly in the field of clinical trials. Our research highlights the need when health choices are being made to couple information provision with counselling for patients when health choices are being made to help patients chose an option that best accommodates their physical health and personal interpretation of the risk they may be taking. This would provide a conduit between the patient's 'emotion-risk assemblage' and the intended scientific rationale of the medical research and ensure a space for patient and medical professionals to unpack and discuss the best available option.

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742
743 **Table 1:**

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PARTICIPANTS

TABLE 1									
Pseudonym	***Age***	**Cadaveric**	**Living**	**Location**	**Transplant(s)**	**Partner**	**Children**	**Dialysis**	***Risk Level***
Robert	*42*			South Yorks (SY)	2009	Yes	One, 9	18 months	**10%**
Lucy	*35*			South-East (SE)	2000	No	No	7 years	**20%**
Colin	*63*			SE	2007	No	Two, 18+	12 months	**40%**
Miranda	*59*			SY	1996	Yes	No	6 months	**0%**
Jessica	*28*			SE	1997	Yes	Pregnant	12 months	**2%**
James	*27*			SE	2000	Yes	No	11 months	**0%**
Imelda	*50*			SE	2006	No	No	2 years	**20%**
Lorna	*60*			SE	2002	No	Two, 18+	1.25 years	**1%**
Graham	*68*			SE	2001	Yes	Two, 18+	<year	**50%**
Sanji	*56*			SE	1999	Yes	Two, 18+	<year	**0%**
Georgina	*64*			SE	1990	No	One, 18+	No	**35%**
Betty	*55*			SE	1982 & 1985	Yes	Two	4.5 years	**3%**
Alan	*50*			SE	1997	Yes	Two, 18+	No	**50%**
Jenny	*41*			SE	2004	Yes	One, 9	9 months	**10%**
Luke	*52*			SE	2005	Yes	Three, 18 +	12 months	**0%**
Kate	*58*			SE	1988	Yes	Stepson, 18+	9 years	**5%**
Oliver	*34*			SE	2003	No	No	12 months	**50%**
Jack	*61*			SE	1970 & 1998	Yes	No	26 years	**0%**
William	*54*			SE	2000	Yes	Two, 18+	<year	**50%**
Mark	*51*			SE	1999	No	No	<year	**50%**
Dawn	*48*			SE	2004	Yes	No	2 years	**0%**
Paul	*44*			SE	2008	Yes	Two, 6 and 9	No	**0%**
Alice	*42*			SE	2007	Yes	No	No	**25%**
Tom	*37*			SE	2006	No	No	8 years	**25%**

Understanding kidney transplant patients' treatment choices: the interaction of emotion with medical and social influences on risk preferences

Highlights

Biomarker tests of graft tolerance cannot be 100% accurate, risking kidney rejection

Dialysis concerns, familial views, trust & 'gift exchange' shaped decision-making

These experiences & circumstances were intertwined with emotional influences

Patients' decision-making supports the notion of Lupton's 'emotion-risk assemblage'

This assemblage highlights a tension with medical frameworks and medical research

Keywords: United Kingdom, Kidney transplantation, biomarker, risk, emotion, social influences, 'gift exchange'; trust